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General Practitioners' and General Practice Nurses' Self-reported Practice at the End of Life: Delivery, communication, coordination, and multidisciplinary care –a systematic review

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ABSTRACT

Background General Practitioners (GPs) and General Practice Nurses (GPNs) face increasing demands to provide end of life care (EoLC) as the population ages. To enhance primary palliative care (PC), the care they provide needs to be understood to inform best practice models of care.

Objective To provide a comprehensive description of the self-reported role and performance of GPs and GPNs in (1) specific medical/nursing roles; (2) communication; (3) care coordination; (4) access and out-of-hours care; and (5) multidisciplinary care.

Method Systematic literature review. Data included papers (2000 to 2017) sought from Medline, Psychinfo, Embase, Joanna Briggs Institute and Cochrane databases.

Results From 6209 journal articles, 29 reviewed papers reported the GP and GPNs role in EoLC or PC practice. GPs report a central role in symptom management, treatment withdrawal, non-malignant disease management and terminal sedation. Information provision included breaking bad news, prognosis and place of death. Psychosocial concerns were often addressed. Quality of communication depended on GP-patient relationships and GP skills. Challenges were: unrealistic patient and family expectations, family conflict and lack of advance care planning. GPs often delayed end-of-life discussions until three months before death. Home visits were common, but less so for urban, female and part-time GPs. GPs coordinated care with secondary care, but in some cases parallel care occurred. Trust in, and availability of the GP was critical for shared care. There was minimal reference to GPNs roles.

Conclusions: GPs play a critical role in palliative care. More work is required on the role of GPNs, case finding, and models to promote shared care, home visits and out-of-hours services.

INTRODUCTION

Primary care practitioners - General Practitioners (GPs) or family physicians (hereafter termed GPs) and general practice nurses (GPNs) are central to the provision of person-centred palliative care (PC) to improve the quality of life of patients, and to prevent and relieve suffering.[1] GPs are adept at general medicine and develop clinical relationships with patients and carers which allows an understanding of their needs. They are also knowledgeable of the health and social services available in the community.[2] Most people visit a GP regularly and GPs feel that caring for palliative patients is a key role.[3] In Australia, over 80% of GPs report providing end-of-life care (EoLC) for at least one person in the past year.[4 5]

The role of GPNs has grown substantially in recent years as the value of a multidisciplinary team approach has been more widely recognised. The World Health Organisation definition of primary care highlights the role of first point of contact and comprehensive general care of all people within a community.[6] A primary care team at its heart has a GP and a GPN.[6] Murray et al's view of that palliative care should be available to all people across all diseases, all dimensions of the person, in all settings and all countries[7], accords with the WHO view that high quality end of life care is a basic human right. [8 9] This can only be achieved with active involvement of primary care worldwide.

To deliver quality PC, GPs have to identify the patient with EoLC needs, then provide skilled management of co-morbidities while reducing the risk of complications, address psychosocial issues, and liaising with family and other health professionals as well as ensuring the patient's end-of-life wishes and caregiver needs are considered.[10] Often the care requires a multidisciplinary approach[11] with hospital-based consultants, inpatient services and community services. The GP and/or GPN may be leading or be involved in the co-ordination of this care.

To ensure GPs and GPNs continue to build capacity in providing PC within the community,[12] we have sought to improve our understanding of the role of these professionals in the delivery of EoLC. In 2002, a systematic review was published on how well GPs provide EoLC.[3] To date this is the only attempt to bring together the world literature on GP performance on end of life care. However, extensive work on the role of primary care at the end of life has been done in many settings worldwide since that time. While national health systems dictate the nature and role of general practice and primary palliative care to some extent, there are central tasks and roles that are common worldwide.[13]

To facilitate GPs' and GPNs' build capacity in providing PC within the community,[12] we have sought to integrate the literature on general practice palliative care that has been generated since the 2002 systematic review. To this end we have conducted a systematic review of literature published from 2000 to October 2017. The review sought to answer two major questions: (1) How well do GPs and GPNs deliver EoLC; and (2) what are the facilitators and barriers to the involvement of GPs and GPNs in providing EoLC? This publication is the third of a five part of series,[14 15] and explores the following questions: How do GPs and GPNs perceive their practice of PC?; and, do they do what they say they do? The review is subdivided into the themes of specific medical roles, psychosocial care, communication and relationship development, access, and co-ordinated and multidisciplinary care.

METHODS

We conducted a systematic review to critically appraise the effectiveness of care provided by GPs and GPNs in the care of patients approaching the end of life. A protocol for the search was generated by the team in consultation with a health librarian.

Phenomena of interest: We included studies of physical and psychosocial components of PC directly delivered through general practice by a GP and/or GPN; or multidisciplinary PC teams involving GPs or GPNs, or models of integrated care that directly involved a GP and/or GPN.

Inclusion criteria

Types of participants: We sought studies of GPs and GPNs working within general practices. We included studies with patients aged ≥18 years, suffering from advanced malignant or non-malignant illness, no longer responding to curative or maintenance treatment, and who required treatment with a palliative intent.

Types of studies: This review included the following types of studies published in English:

1. Randomised individual or cluster controlled trials (RCTs)
2. Non-randomised controlled trials (CCTs)
3. Controlled before and after studies (CBAs)

4. Qualitative studies (phenomenology using semi-structured interviewing or focus groups) (QUALs)
5. Other (e.g. cohort studies, questionnaire studies)

We excluded papers that did not report primary research findings, including editorials and opinion pieces.

Types of outcomes: The overall review sought studies that included one or more of the following outcomes:

1. GP and/or GPN outcomes:
    a. Extent of GP and/or GPN involvement in PC delivery
    b. Type of care delivered by GP and/or GPN
    c. Type of advanced conditions receiving PC from a GP or GPN
    d. Promoters and barriers to delivery of PC by a GP or GPN
    e. GP or GPN confidence in providing PC
    f. GP or GPN gaps in knowledge in providing PC

2. Process outcomes:
    a. Extent and nature of GP or GPN interactions with multidisciplinary teams including PC specialists and hospices in the delivery of PC
    b. Out of office hours care

3. Patient /carer outcomes:
    a. Preferred place of death
    b. Satisfaction with care
    c. Symptom management including pain
    d. Quality of life
    e. Carer stress
    f. ACP (ACP)
    g. Psychosocial (mood, anxiety)

Search strategy

We searched Medline, Psychinfo, Embase, Joanna Briggs Institute and Cochrane databases from 2000 to October 2017. The search strategy was based on that used in Mitchell's 2002 systematic review [3] and team discussion. The full search strategy is presented in Appendix 1.

The EndNote 8.0 reference package (Clarivate Analytics, USA) was used to manage references. The initial database search was by single review of Titles and Abstracts in these databases, and hand-searching references in systematic reviews was conducted by JFF, BW and HN. This initial search yielded 6209 articles after duplicates were removed. Titles and abstracts were then reviewed by both JFF and BW to 2014, and GM and HN to 2017: 5732 articles were excluded, leaving 474 articles for full text review. This included articles with a relevant title but no abstract. Two authors conducted independent assessment of each article, following the protocol. Any disagreements were resolved by discussion between the two authors or by arbitration by a third author if necessary. A further 209 articles were excluded after this process, leaving 265 articles for analysis. The Endnote library was downloaded into EPPI Reviewer4 (EPPI-Centre, University of London) a multi-user web-based application for managing and analysing data for use in research synthesis.

Quality Assessment

Each article was assessed by two authors for quality using a tool relevant to the study type: JADAD-RCT[16] for randomised controlled trials; the Critical Appraisal Skills Programme (CASP) for qualitative research[17]; the Newcastle-Ottawa Quality Assessment Scale (NOS) for cohort studies[18] and the NOS for cross-sectional studies[18]. Discrepancies in ratings were resolved by discussion, or by arbitration by a third author if necessary.

Analysis and reporting

Because the number of articles was unexpectedly high we decided to subdivide the papers into categories that would inform a series of separate manuscripts. This approach was chosen to allow an appropriate level of depth for the analysis of the role of primary care at the end of life. All authors were

asked to allocate the articles they reviewed to the different categories, and discussion between the authors ended in agreement for the five following categories:

1. GP and GPN performance of palliative care: symptom management;
2. GP and GPN performance of palliative care: patient and carer perspectives, ACP, and the preferred place of death;
3. How do GPs and GPNs perceive their practice of PC, and do they do what they say they do?
4. Barriers and facilitators to involvement in palliative care: at the practitioner, practice and system and policy level; and
5. Models of care aimed at encouraging participation in and integrating primary care practitioners into EoLC.

One paper was planned for each theme, with literature divided into these themes and then allocated to sub-categories. Authors worked in pairs to create a table of evidence and a brief written supporting statement for each sub-category. Papers that appeared relevant to multiple categories or sub-categories were included in multiple papers. The first author of each paper collated the sub-category reports into the final paper. As this is a systematic review, no ethical review was necessary. This paper addresses the third category: How do GPs and GPNs perceive their practice of PC, and do they do what they say they do?

RESULTS

Search results

From 6209 journal articles, 29 papers discussed: 1) Perceived medical and nursing roles; 2) Psychosocial care; 3) Communication and relationship development; 4) GP access, and 5) Coordination and working in multidisciplinary teams. (Figure 1). Details of the aims, methods and quality of included studies are available in online supplementary appendix 2. The detailed findings are presented in online supplementary appendix 3. The subject matter was descriptive and heterogenous. It is reported using narrative synthesis, divided into the above themes.

Insert figure 1 around here.

Perceived Medical Roles

Thirteen studies reported GP self-reported medical management practices. There were six cross-sectional studies, six qualitative studies and one mixed-methods study. Multiple studies were conducted in New Zealand,[19 20] Belgium,[21-24] the Netherlands,[25-27] and one each from Italy,[28],Canada,[29] and the UK.[30] One study compared clinical practice in the Netherlands and Australia.[31] All studies reported GP management and practice, and one study reported the involvement of nurses in decision making.[21]

Significant role in EOLC.

Most GPs perceived they have a significant role in EoLC [24], and are in a better position to do this than specialist colleagues.[22] This role requires continuity of care[26 29] and encompasses all aspects of care for the patient, and support for the family.[22] Patients appreciate this supportive role. [28 29] GPs find delivering PC to be satisfying, but emotionally and intellectually demanding, a time- and energy-consuming task requiring a wide-range of skills.[23 25] GPs value nurses' specific competencies and technical skills, and often delegate specific tasks to meet palliative care needs.[23] GPs were more likely to provide care for older, female and non-malignant cases[24], and have less involvement in cancer cases. People with non-malignant disease were more likely to receive complex specialist medical interventions, and people with cancer more likely to have allied health involvement and less GP involvement.[24]

Case finding.

Only one study discussed identification of patients potentially requiring PC, and registration in a palliative care register (PCR).[30] Patients with non-malignant diseases were 11 times less likely than people with cancer diagnosis to be registered in a PCR,[30] due to unpredictable disease trajectories and uncertain prognostication. Education improved GPs' confidence in identifying and including people with non-malignant diseases on the PCR.[30]

Symptom management.

This section reports the GP practise in symptom control. The effectiveness of GP symptom control at end-of-life is more fully described in a previous review.[15] GPs reported assuming responsibility for important medical decisions within community teams, especially to avoid inappropriate treatments.[28]

Pain management.

GPs described prescribing opioids, up-titrating them to match pain, and continuing opioids in the terminal phase.[19] GPs knew of the need to escalate opioid dose to increasing pain levels.[28] and the importance of ceasing non-essential medicines at the end of life.[19]

Non-malignant disease management.

GPs used symptomatic treatments including opioids, oxygen, diuretics and haloperidol regularly in heart failure management. [27] Specialist cardiology involvement led to more use of specific treatment for heart failure.[27] GPs reported using established guidelines for breathlessness.[19]

Artificial nutrition and hydration.

Both Dutch and Australian GPs were willing to initiate artificial nutrition and hydration (ANH) to end stage dementia patients,[31] but used different definitions of ANH. Australian GPs considered ANH included spoon feeding, and Dutch doctors restricted it to feeding by an interventional procedure.[31] Doctors in both countries only considered ANH in situations where a reversal of an acute illness was possible, and where improvement in quality of life was possible.[31] GPs consulted widely before making a decision to start ANH.[22 31]

Initiating terminal sedation.

GPs would consider terminal sedation (TS) to ensure minimal suffering when other treatments were not effective[28] and there was persistent and unbearable suffering.[21] Patients were not consulted if the GP thought the patient lacked decision making capacity.[20] They believed TS did improve quality of life of selected patients[31], even though the decision may hasten death.[31] Six per cent of respondents prescribed or administered drugs with the explicit aim of inducing death.[20]

Psychosocial care

Seven studies examined psychosocial and spiritual care self-reported by GPs. These came from Australia,[32-34] Belgium,[21 24] Italy[28], and the UK.[35] Three were qualitative studies, two were case studies from a sentinel network study, one was a cluster randomised trial and one a cross-sectional study.

Providing information.

GPs believed they have a major role in being sensitive to and ready to respond to patient and carer concerns. GPs perceived that good communication skills are a core competency of their practice and good GP communication skills were viewed very positively by patients.[28 29] Psychosocial care was commonly offered, particularly as death approached. [24] This care included breaking bad news, and providing information about prognosis and place of death. [28]

Recognising and responding to suffering and psychosocial concerns.

GPs appreciated the level of patient suffering, and believed they helped alleviate suffering.[21] Case conferences dealt directly with emotional care, mood and social isolation[32], but were more concerned about their management of psychosocial symptoms than the nature of the concerns.[34] Emotive cues offered by patients and carers were usually met by information from the GP, with only a quarter of cues receiving an empathetic response.[34] GPs were more likely than clinical specialists to discuss social and emotional problems, and spirituality.[22]

Addressing spiritual concerns.

GPs were certain that addressing spirituality was a core responsibility [35], but many left it to the patient to raise it. GPs only raised spiritual issues when they judged their patient would be receptive to the

subject.[35] Time constraints limited provision of spiritual care.[35] Chaplains and others were involved in about a quarter of cases.[24]

Responding to Bereavement.

GPs were willing to respond to death and have a role in bereavement care, including home visits to surviving family.[28] Whilst GPs reported inadequate training in bereavement, they felt comfortable dealing with it.[33] The Kubler-Ross stages of grief model was the basis for many GPs' understanding of bereavement.[33] Some GPs reported using cognitive behavioural therapy in managing grief.[33] They believed they were competent in recognising complicated grief, but were uncertain about what specialist resources were available. [33]

Communication and Relationship Development with Patients and Family

Ten articles (4 qualitative studies, 6 cross-sectional) discussed the role of communication and relationship development in PC delivery. Studies were conducted in the Netherlands,[25 36 37] Belgium,[23 24] France,[38] the UK,[30 39] Republic of Ireland,[39] and Canada.[29 40]

Key role in communication.

The GPs felt they have an important role in communicating with patients, providing information and involvement in advance care planning (ACP). [25 36 40] Developing and maintaining relationships with patients and carers was important.[23 25 40] Patients stated their GP provided warmth, encouragement and emotional support.[29]

Quality communication with patients and close family/carers.

Factors influencing the quality of communication, and maintaining and developing relationships between GPs and patients and carers included: pre-existing close, but not necessarily long-term, relationships;[29 40] good communication skills and GP experience.[40] Barriers included unrealistic expectations or unresolved differences between family members, physician discomfort, and lack of effective previous ACP.[25 40]

Initiating end-of-life discussions.

The incidence and timing of end-of-life discussions for malignant and non-malignant patients varied. GPs often delayed having them, often until one-month to a week before the patient's death.[36] Palliation replaced cure and life prolongation as the primary goal between three months and one week before death.[24 36] Curative or life prolonging interventions were ceased during that time for cancer patients[37], but more likely in the last month in non-malignant patients.[37] Patients with cancer were more likely than those with non-malignant disease to have PC needs identified by a GP,[40] and more likely to receive care from clinical specialists, informal caregivers, allied health, and multidisciplinary palliative care services.[24] The unpredictable trajectory of the non-malignant conditions caused much of the uncertainty around timely PC referral.[30]

Conducting end-of-life discussions.

GPs discussed end-of-life issues with patients and substitute decision-makers.[40] Facilitators to these discussions were: good working relationships with both the patient and their family, and coherent and stable family attitudes.[23] Facilitators of conflict included: families feeling pressured to make treatment withdrawal decisions, and differing opinion about who has the right to make these decisions.[40]

The GPs' role in conflict resolution was critical for achieving a good death, by building trust and rapport, listening, and making informed shared decisions with the family,[40] and decisions to withdraw suboptimal and inappropriate medications in people with reduced life expectancy.[39] Most GPs believed they can contribute usefully to treatment withdrawal decisions in hospitals, but only a quarter were contacted by hospital physicians, and of these, only a third actively participated in the decision.[38]

Abarshi et al[36] examined end-of-life discussions between GPs and 252 patients with advanced malignant and non-malignant disease. They asked if ten key issues were discussed.[36] Of these, GPs discussed physical and psychological problems with the patients most frequently, and social and spiritual issues least frequently.[24 36] All ten end-of-life issues were only discussed with a few patients, and the number of issues discussed was higher in cancer patients than non-malignant conditions.[36]

Access to the GP, home visits, and out-of-hours services

Nine articles (2 qualitative studies, 5 cross-sectional surveys, 1 mixed methods, 1 quasi-experimental trial) discussed availability of GP services. Studies were conducted in Canada,[29] Italy,[28] The UK,[41-43] the Netherlands,[26 44] and Australia.[32 45]

Being accessible in person and by phone.

GPs provided PC in a variety of forms: clinic, home visits, phone support, case conferencing with specialists, and out of hours support[32 43]. In Ireland, GPs provided a mean of 5.4 home visits, 1.8 clinic visits, and 3.6 episodes of phone support per deceased individual in the final three months of life.[43]

Patients found phone support from GPs particularly beneficial,[29] reducing anxiety and allowing them to address medical issues proactively.[28 29] There were limits to that availability, with less availability on weekends, particularly overnight.[28] Patients and carers appreciated when GPs made themselves available by phone or offered to visit, but were irritated if they did not answer calls or respond promptly to emergencies.[41]

Providing home visits.

The majority of respondent GPs from one Italian[28] and one rural Australian study[45] stated that they would visit patients at home in the terminal phase of an illness. Many patients in a Canadian study were often not aware of this service, believing few GPs did home visits.[29] Willingness to provide out of hours care ranged from 86% of Dutch GPs,[26] to 68% of Australian urban GPs.[45] Most GPs considered providing home terminal care was valuable for both the GP and family.[26] Patients and carers rarely misused this increased GP availability. GPs who provided after hours care were more likely to be male, self-employed, working in rural areas, and working in a small practice.[26]

Deputising services

GP deputising services were commonly involved in the care of palliative patients,[42 44] both at home and in aged care facilities. They reported significant barriers to provision, including: clinical notes commonly unavailable, vague or inadequate; and management plans not fully communicated.[42 44] Inadequate clinical documentation increased transfers to hospital.[42 44] UK patients and carers were reluctant to contact out of hours services[42]. Difficulties identified by patients and carers included: conveying medical

information by telephone; unacceptable waiting times and delays; speaking with unknown people; and, lack of awareness by the doctor of community resources.[42]

Coordination and Working in Multidisciplinary Teams

Eleven studies (4 qualitative studies, 5 cross-sectional surveys, 1 quasi-experimental, 1 cluster RCT) reported on the GPs role in coordinating palliative care, including working in multidisciplinary teams and liaising with specialist PC services. Studies were conducted in the Netherlands,[25 46], Belgium[23], Canada[29], New Zealand[19 20], the UK[43 47], Italy[28] and Australia[32 34].

Coordinating palliative care tasks.

GPs often coordinated the provision of end-of-life care, but other health professionals, including community nurses could be the team coordinator. Some GPs did not see care coordination as their role.[25] Cancer patients described varying patterns of care coordination.[29] Cancer patients noted specialist and GP care was segregated, with oncology services administering disease-modifying treatment, and then only returning patients to GPs for PC (or not at all).[29] Parallel care occurred when the patient continued to see the GP and specialist care separately. Communication was formal, but each doctor acted independently.[29] Shared care occurred when the GP care was actively integrated with specialist care.[29]

Belgian multidisciplinary palliative home care teams (PHCTs) include GPs with specialised training in PC, who work with the patient's GP to provide care.[23] GPs found PHCTs moderated their workload when caring for a palliative patient. Some GPs found these teams were most useful for complex cases.[23] GPs believe coordinating PHCTs was part of their job.[23] For the PHCTs to work optimally, GPs emphasised the importance of sound PC knowledge in all team members, understanding the competencies of each member to ensure appropriate task allocation, agreed care goals and clear task descriptions.[23]

Liaising with patients, carers and other health professionals to deliver care.

Palliative care requires collaboration with patient, family, and professionals (GPs, community based nurses, other doctors, and other health professionals) ,[28 43 46] with a mean of four informal and formal

caregivers involved per individual patient.[46] Sharing care and respecting the skills of each health professional were essential for effective collaborative relationships.[19] The closer this relationship, the more GPs trusted the clinical care provided by the specialist team, and the more willing they were to collaborate.[19] Whilst specialist teams perceived they worked collaboratively with GPs, some GPs felt excluded from the delivery of care[19]. However, collaboration with specialist teams improved the knowledge, skills and practice of GPNs.[32] Palliative care nurse coordinators and specialist/generalist case conferences promoted collaboration and information sharing between specialist PC and general practice teams.[19 32]

GP collaboration was more likely with other health professionals if the patient had a malignant disease or if the person required physical, psychosocial or spiritual care.[46] Younger patients experienced more collaborative care.[46]

Referring to and working with specialist services.

GPs described that communicating with specialists and coordinating care for PC patients are important roles.[19 23 25 28] Patients felt GP-specialist communication was important, but not always done well.[29] Some GPs, particularly part-time GPs and solo GPs, also found engaging with specialist teams challenging.[19]

GPs expected to be kept in the loop to ensure good patient care, and to build trust between the clinicians.[19] GPs wanted clarity from specialist services about the level of support they would provide, and to participate in decisions related to patient hospitalisation and treatment.[47] The role of the GP in an interprofessional team was largely determined by the depth of their knowledge of the patient and family, and the continuity of care they offered.[19] Some GPs' PC skills may need enhancement, due to the low frequency of caring for such patients.[19]

Whilst most GPs worked in an extended team with specialist services, some GPs preferred to transfer care entirely to PC specialists[47] and others managed some patients without involvement of specialist PC services. The level of specialist support was dependent in part on the experience of the GP in symptom management and the quality of local services.[47] Some GPs said working with specialist teams was not always collaborative.[19]

A loss of confidence in GPs by specialists

Two New Zealand publications, thirteen years apart, implied a change in the GP's role over time.[19 20] In the later publication, GPs reported some de-skilling and a sense of being considered lower in the hierarchy than specialist colleagues.[19 20] Specialist teams described barriers to communication with GPs, particularly being unavailable by phone, as being the greatest impediment to integrated care.[19] Factors that improved collaboration with specialists included regular informal communications from specialists to GPs, case conference between GPs and specialists,[32] trust and personal relationships between team members[19], perceived competence of team members and the team arrangements[23]. Barriers included different cultures of generalists and specialists, and GPs not feeling involved or their input appreciated.[19] A history of trust between GPs and the specialist service led to more willingness by both parties to cover gaps in care.[19]

Conducting multidisciplinary case conferences

A workable model to coordinate multidisciplinary care around the needs of PC patients and carers utilises inter-professional case conferences between the GP, a specialist palliative medicine physician and other team members, and sometimes the patient and/or carer,[32 34\] and is conducted using communications technology. Preparation prior to the case conference, including sharing of clinical data, is highly desirable and facilitates the conference.[34] Physical symptom management occupies much of the discussion.[34] The outcomes of case conferences are improved coordination and communication and an agreed, comprehensive, proactive care plan (physical, social support, emotional and personal control domains), with clear roles of clinical staff delineated.[32 34] Case conferences between GPs and specialists were considered effective in generating care plans and facilitating positive patient outcomes.[32 34] Both GP and GPNs experienced improved levels of knowledge and skills from participation.[34]

DISCUSSION

Summary of findings

As one component of a series update to Mitchell's 2002 systematic review,[3] this review reports the narrative synthesis of 29 papers describing the factors related to the self-reported role of GPs and GPNs in delivering PC. The review has categorised these roles within the areas of perceived medical roles;

psychosocial care; communication and relationship development with patients and families, including end-of-life conversations; GP access, home visits and out-of-hours services, and coordination and working in multidisciplinary teams.

Most GPs believe they have a significant and effective role in delivering PC, and despite the emotional, intellectual, and time demands, it is a satisfying role. The role is diverse, and includes symptom management[15], pain management and non-malignant disease management. A core competency of GPs is communication with patients and families which is sensitive to their emotive cues. Reasons for variability in the quality of GP-patient communication were identified. More ethnically diverse populations,[48] and rising number of people with dementia[49] challenged GP's communication skills. Conversations such as breaking bad news, and discussing prognosis and place of death were often considered difficult. GPs also played a role in bereavement care and recognising complicated grief, but reported a lack of training in bereavement care. Spiritual issues were addressed by GPs, but only if the patient raised a concern or felt that the patient was receptive.

GPs reported being active in ACP and providing information to patients and families. End-of-life discussions, including the development of ACPs to guide anticipatory decision-making, were often not initiated by the GP until close to death

For patients nearing the end-of-life, GPs provided telephone consultations or offered a home visit, which reduced anxiety and increased proactive care. However, patients were also frustrated by unanswered calls and GPs' failure to respond promptly. While the majority of GPs provided home visits, there was variation between countries. Male,rural, full-time and small practice doctors are more likely to provide home visits for patients in the final stage of life.[50] Changing demographics and work practices of the GP population[26 50] may alter the willingness to continue to provide home visits and after hours support in the future. GPs commonly used deputising services to ensure care for palliative patients out-of-hours, which could lead to a reduction in quality of care due to communication issues between the service and the patient's GP. Being treated by an unfamiliar doctor in that situation could prove unsettling for patients and their carers. [51]

Only a single study reported the involvement of nurses in end-of-life decision making.[21]

Comparision with the literature

Much has changed about palliative care, and hence the role of GPs since the 2002 review. Among these changes are: the development of advance care planning, consideration of more formal multidisciplinary care including primary care, deskilling and altered confidence in GP and GPN ability to perform EoLC, recognition that EoLC relates to non-malignant disease as well as cancer, and detailed consideration of terminal sedation and artificial nutrition and hydration. This series of reviews documents the GP roles relating to these changes.

Due to the complexity of PC provision and increasing demand, the roles of the GP and GPN are central to coordinating integrated services.[2] We found GPs liaise broadly with family carers, and primary and secondary health professionals such as specialist PC teams, to deliver multidisciplinary care. They sometimes coordinate primary health care teams. Clear roles and trust between health professionals was crucial for the GP to fulfil a leadership role. However, some aspects of secondary care such as specialised cancer care led to primary care being siloed, leading to a potential de-skilling of the GP and a loss of professional relationships.[24] The use of case conferences could be a possible solution to enhance the primary and secondary interface between the GP, primary (community-based) and secondary health professionals, patients and carers, and develop an agreed shared care plan.[11 32 34 52] With growing demand limiting the resources of specialist PC services, the role of the GP in PC provision will increase. Improved integration between primary and secondary care has been shown to maintain patient performance status and reduce hospitalisation.[11 53] Therefore, policy and education that enhances GP leadership in coordinated care, improves the primary PC skill-set, supports information technology to allow sharing between care settings and providers, and increases the availability of community support services is likely to support people to be cared for at home and die in their place of choice.

Many nations have ageing populations with associated increases in disease burden. Most people will die due to frailty, multimorbidity, organ failure, dementia, and malignant disease.[54 55] One of the major challenges in optimal EoLC within primary care is the early identification of those at risk of dying which allows present and anticipatory PC needs to be addressed in a timely manner. In this review, only a single study investigated case finding in PC, and noted that patients with non-malignant disease were substantially less likely to be recorded on a PC registry. EoLC planning is difficult, especially for those

with non-malignant conditions due to uncertain trajectory.[54 55] To aid identification of patients who can benefit from PC, a number of screening instruments have been developed.[56] Early investigations into the accuracy and appropriateness of the instruments were recently evaluated in primary and residential care settings with mixed findings.[57 58]

GPs reported that they value the PC proficiencies and skills provided by GPNs, and often delegate specific tasks including coordination of community PC delivery.[23 25] GPNs improved their skill sets by collaborating with specialist teams through case conferencing.[32 34] Overall, there is a paucity of research in the role of GPNs in PC delivery. This may reflect the low prevalence of dying in primary care, with GPs playing the key role in diagnosis and end-of-life care provision.

Nursing care and palliative care share common approaches in providing comprehensive care to support the holistic needs of patients and caregivers, including symptom management, communication, and advocacy. Enhanced education, training, and administrative support is required to overcome barriers and assist nurses to engage in palliative care for their patients.[59] Once barriers are overcome, GPNs can play a beneficial role in undertaking advanced care planning.[60] GPNs already play a significant role in co-ordinating and working with multidisciplinary teams, and providing support for people with advanced chronic disease and frailty.[61-64] An expanding role for GPNs to be involved in ACP is being explored.[65] Studies from Australia and Canada have recently described the role of the nurse practitioner or nurse specialist in PC delivery in the community and residential care, with limited authority to prescribe medications, coordinate care, and develop care plans with the GP and other multidisciplinary team members.[52 66] These enhanced roles have the potential to address the increasing PC needs of the ageing population, and in under-resourced rural areas.

Strengths and limitations

This systematic review provides a comprehensive understanding of the role of GPs and GPNs in the practice of primary PC with a focus on delivery, communication, coordination, and multidisciplinary care. This review presents findings within a pre-planned series of systematic reviews on the role of primary care practitioners in PC[14 15] and is an update and broadening of a previous systematic review on the role of GPs in palliative care delivery.[3] The review followed rigorous systematic review methodology with an extensive search in the major databases. The majority of included papers are observational or

qualitative. Due to the nature of primary PC, including low volume per practitioner, RCTs are not always practical or ethical. In view of the heterogeneous nature of research within PC, we employed a narrative strategy to synthesise both qualitative and quantitative findings. While these approaches can provide descriptive data and associations, and provide in-depth understanding of health practitioners, patients and carers experiences, it does limit the generalisability of the findings. Due to the heterogeneous methodology used in the studies analysed, it is not applicable to combine data by meta-analysis. Further, the review is limited to English-speaking articles only, thereby limiting the understanding of primary PC in non-English speaking countries.

Unanswered questions and future research

Caring for a patient at end-of-life is complex, and GPs require multiple competencies and skills. More research is required to understand how GPs can identify malignant and non-malignant patients with PC needs at the most appropriate time to provide optimal treatment, and how best to support GPs in their co-ordination role within multidisciplinary care. There is a gap in the literature regarding the role of the GPN in providing PC and how they share care with the GP and other professionals. Research is required to develop strategies to support GPs to provide home visits. Given a significant proportion of EoLC patients access out-of-hours services,[51] models of care need to be evaluated on outcomes such as quality of care; GP, patient and family satisfaction; and, information sharing between services. With an increased emphasis on shared care between primary and secondary care, research into interventions to enhance the interface, reduce parallel care, improve trust and skill appreciation, would be beneficial.

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Competing interest statement

There are no competing interests to declare.

Access to data

The full protocol and dataset can be obtained on reasonable request from the corresponding author.

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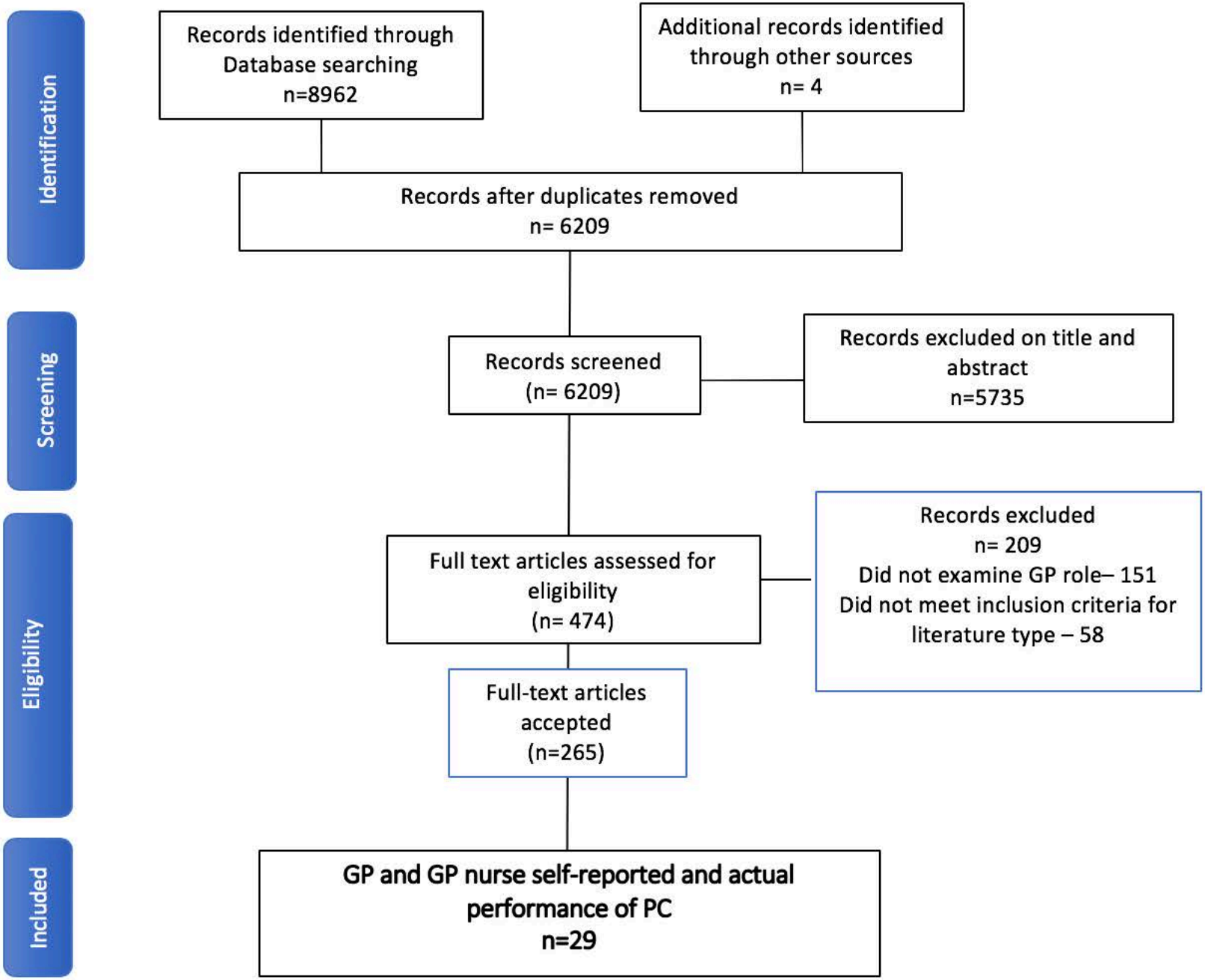
Identification
Screening
Eligibility
Included
Records identified through Database searching n=8962
Additional records identified through other sources n= 4
Records after duplicates removed n= 6209
Records screened (n= 6209)
Records excluded on title and abstract n=5735
Full text articles assessed for eligibility (n= 474)
Records excluded n= 209 Did not examine GP role– 151 Did not meet inclusion criteria for literature type – 58
Full-text articles accepted (n=265)
GP and GP nurse self-reported and actual performance of PC n=29

Appendix 1. Search strategy

The search strategy for MEDLINE (Ovid) is as follows, with number of hits in brackets, and was adapted for other databases

1 exp Palliative Care/ (40025)

2 exp Terminal Care/ (41427)

3 exp Hospice Care/ (4594)

4 palliat*.tw. (49152)

5 hospice*.tw. (8644)

6 (terminal* and (care or caring or ill*)).tw. (14524)

7 ((advanced or 'end stage' or terminal*) adj4 (disease* or illness* or cancer* or malignan*)).tw. (115084)

8 ('last year of life' or lyol or 'life's end' or 'end of life').tw. (12394)

9 or/1-8 (216562)

10 (child* or adolescent* or infant* or baby or babies or neonat* or juvenil* or pediatric* or paediatric* or matern*).ti. (1028881)

11 9 not 10 (208790)

12 exp Primary Health Care/ (78629)

13 exp General Practice/ (63643)

14 exp General Practitioners/ (1880)

15 exp Physicians, Family/ (14718)

16 exp Family Practice/ (60080)

17 general practice.tw. (28839)

18 (family practice or family medicine).tw. (13017)

19 (general practitioner* or gp* or general physician*).tw. (146922)

20 (family physician* or family doctor* or family practitioner*).tw. (16343)

21 or/12-20 (288767)

22 exp Family Nurse Practitioners/ (8)

23 exp Nurses, Community Health/ (46)

24 exp Patient Care Team/ (54259)

25 exp Nutritionists/ (49)

26 exp Physical Therapists/ (329)

27 exp Social Work/ (15085)

28 exp Psychology/ (58272)

29 or/22-28 (125712)

30 11 and 21 (4215)

31 30 and 29 (366)

32 30 or 31 (4215)

33 limit 32 to English (3723)

34 limit 33 to yr="2000 -Current" (2666)

Appendix 2: Details of the aims, methods and quality of included studies (by theme)

Study, author, date & location	Study design & aim	Setting, sample size & participant characteristics	Methods	Quality assessment
2.1 Case finding and Care delivery				
Survey of Italian general practitioners: knowledge, opinions, and activities of palliative care Beccaro, 2013[29] Italy	Design: Cross-sectional survey Aim: To conduct a national population-based study of the knowledge and activities of GPs in palliative care	Setting: General practice Sample size: n=1690 Participants: GPs	Questionnaire administered by phone	NOS Cross-sectional[1] 6/10 (three possible points not relevant)
Symptoms in patients receiving palliative care in general practice Borgsteede, 2007[67] Netherlands	Design: Cross-sectional survey Aim: To determine which patients who died in previous year received palliative care.	Setting: General practice Sample size: n=2194 Participants: Patients	Chart review of all deaths in previous year who received palliative care in the last 3 months of life	NOS Cross-sectional 6/10
Reducing inequalities in care for patients with non-malignant diseases Dalkin, 2016[31] UK	Design: Mixed methods Aim: To find whether, how, and under what circumstances palliative care registrations are made for patients with non-malignant diseases in primary care.	Setting: General Practice Sample size: n=14 Participants: General Practices	Quantitative data analysis of palliative care registrations across GP practices, qualitative focus groups on effect of integrated care pathway on non-malignant palliative care registrations	NOS Cross-sectional 10/10
Assessing and improving out-of-hours palliative care in a deprived community Fergus, 2010[43] UK	Design: Mixed methods Aim: To evaluate GP practices, challenges and improvements in providing after hours care for patients at the end of life.	Setting: Hospice, General Practice and health professional offices Sample size: n=21 Participants: Patients, carer, GPs, nurses, nurse advisers, palliative care specialists	Review of population statistics, qualitative interviews	CASP[2] 10/10

GP out-of-hours medical care for terminally ill patients Hoexum, 2102[27] The Netherlands	Design: Cross-sectional survey. Aim: To determine to which level GPs are available out of hours for their own terminally ill patients and to elicit what factors are relevant to this availability	Setting: General Practice Sample size: n=327 Participants: GPs	Questionnaire	NOS Cross-sectional 4/10 (two possible points not relevant)
General practice and specialist palliative care teams: an exploration of their working relationship from the perspective of clinical staff working in New Zealand Keane, 2017[20] New Zealand	Design: Qualitative study Aim: To explore how general practice and specialist palliative care teams (SPCTs) view their relationship in terms of partnership working	Setting: General practice and Specialist Palliative Care Teams Sample size: n=35 Participants: 6 GPs, 5 palliative care consultants, 3 allied health, 13 nurses, 8 educators and managers	Qualitative focus groups	CASP 10/10
Physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium Meeussen, 2010[22] Belgium	Design: Mixed methods Aim: To identify GP practice in the decision to, and implement requests to hasten death.	Setting: General practice Sample size: n=13 Participants: GPs	Standardized face-to-face interviews	CASP 10/10
Information disclosure to terminally ill patients and their relatives: Self-reported practice of Belgian clinical specialists and general practitioners Michiels, 2009[23] Belgium	Design: Cross-sectional survey Aim: To examine physicians' practices regarding information disclosure to terminally ill patients and to their relatives, without informing the patient.	Setting: Hospitals and General Practice Sample size: 1748 medical specialists, 257 GPs Participants: Belgian specialists and GPs	Trans-national survey, Europe and Australia.	NOS Cross-sectional 7/10 (two possible points not relevant)

Case conferences between general practitioners and specialist teams to plan end of life care of people with end stage heart failure and lung disease: an exploratory pilot study Mitchell, 2014[33] Australia	Design: Pilot intervention study Aim: To evaluate a pilot of the impact of a single case conference between GP and specialist heart and lung disease services to develop a palliative care plan.	Setting: General Practice Sample size: n=21 Participants: GPs	Pilot intervention study	NOS Cohort[3] 4/10
Deaths in general practice: An Irish national profile Ni Riain, 2001[44] Ireland	Design: Practice audit Aim: To explore general practice experience of the care of dying patients.	Setting: General Practice Sample size: n=103 Participants: GPs	Standardized audit tool	NOS Cross-sectional 9/10
Family physicians and cancer care. Palliative care patients' perspective Norman, 2001[30] Canada	Design: Qualitative study Aim: 1) To explore factors that affect the integrity of palliative cancer patients' relationships with family physicians 2) To ascertain their perceptions of their family physicians roles in their care	Setting: Palliative care wards Sample size: n=25 Participants: Patients	Semi-structured interviews	CASP 8/10
Palliative care in the hinterlands: A description of existing services and doctors' attitudes Periera, 2005[46] Australia	Design: Cross-sectional survey Aim: To describe palliative care services as they exist in rural Midwest New South Wales	Setting: General Practice Sample size: n=19 Participants: GPs	Questionnaire	NOS Cross-sectional 4/10

Out-of-hours palliative care provided by GP co-operatives: Availability, content and effect of transferred information Schweitzer, 2009[45] The Netherlands	Design: Cross-sectional survey Aim: To assess the availability, content and effect of information transferred to the GP co-operatives	Setting: Dutch GP after hours cooperative Sample size: n=553 Participants: Patients phoning an out-of-hours service	Cross-sectional exploratory study of all palliative care phone calls during a period of one year to a GP co-operative	NOS Cross-sectional 6/10 (one characteristic worth up to 2 points not relevant.)
2.2 Perceived Medical Roles				
Primary care services received during terminal illness Beaver, 2000[42] UK	Design: Qualitative study Aim: What primary care services were received and whether there were helpful and/or unhelpful aspects of service provision	Setting: Community Sample size: n = 36 Participants: Fifteen people with terminal illness, ten lay carers, eleven bereaved carers.	Qualitative interviews.	CASP 9/9
Survey of Italian general practitioners: knowledge, opinions, and activities of palliative care Beccaro, 2013[29] Italy	Design: Cross-sectional survey Aim: To conduct a national population-based study of the knowledge and activities of GPs in palliative care	Setting: General practice Sample size: n=1690 Participants: GPs	Questionnaire administered by phone	NOS Cross-sectional 6/10 (three possible points not relevant)

Artificial nutrition and hydration for patients (ANH) with advanced dementia: Perspectives from medical practitioners in the Netherlands and Australia Buiting, 2011[32] Australia, Netherlands	Design: Qualitative study Aim: To describe the views of Australian and Dutch GPs about initiating ANH in advanced dementia patients	Setting: General Practice Sample size: n=26 Participants: 15 Dutch and 16 Australian GPs	In-depth interviews	CASP 9/9
General practice and specialist palliative care teams: an exploration of their working relationship from the perspective of clinical staff working in New Zealand Keane, 2017[20] New Zealand	Design: Qualitative study Aim: To explore how general practice and specialist palliative care teams (SPCTs) view their relationship in terms of partnership working	Setting: General practice and Specialist Palliative Care Teams Sample size: n=35 Participants: 6 GPs, 5 palliative care consultants, 3 allied health, 13 nurses, 8 educators and managers	Qualitative focus groups	CASP 10/10
Physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium Meeussen, 2010[22] Belgium	Design: Mixed methods Aim: To identify GP practice in the decision to, and implement requests to hasten death.	Setting: General practice Sample size: n=13 Participants: GPs	Standardized face-to-face interviews	CASP 10/10

Case conferences between general practitioners and specialist teams to plan end of life care of people with end stage heart failure and lung disease: an exploratory pilot study Mitchell, 2014[33] Australia	Design: Pilot intervention study Aim: To evaluate a pilot of the impact of a single case conference between GP and specialist heart and lung disease services to develop a palliative care plan.	Setting: General Practice Sample size: n=21 Participants: GPs	Pilot intervention study	NOS Cohort 4/10
Survey of GP medical decisions at the end of life Mitchell, 2004[21] New Zealand	Design: Cross-sectional survey Aim: To explore type and incidence of medical decisions at the end of life that hasten death made by general practitioners in New Zealand, within the context of access to palliative care.	Setting: General Practice Sample size: n=1255 Participants: GPs	National survey	NOS Cross-sectional 7/10
General Practitioners' experiences of bereavement care and their educational support needs: a qualitative study O'Connor, 2014[34] Australia	Design: Qualitative study Aim: To explore GPs' understandings of bereavement care and their education and professional development needs in relation to bereavement care	Setting: General Practice Sample size: n=17 Participants: GPs	Qualitative	CASP 9/10
Primary care patients with heart failure in the last year of their life Rutten, 2012[28] The Netherlands	Design: Retrospective observational study Aim: To assess the management of primary care patients with HF in their last year of life.	Setting: General Practice Sample size: n=399 Participants: Patients who died from heart failure.	Chart review	NOS Cross-sectional 7/10 (one characteristic worth up to 2 points not relevant.)

Case conferences in palliative care Shelby-James, 2012[35] Australia	Design: Qualitative study Aim: To define the content and themes of palliative care case conferences.	Setting: General Practice Sample size: n=17 Participants: Seventeen case conferences- GPs specialist palliative care GPs, specialists and nurses, patients/carers.	Content analysis of transcribed case conferences	CASP 9/10
Care for Patients in the Last Months of Life The Belgian Sentinel Network Monitoring End-of-Life Care Study Van den Block, 2008[25] Belgium	Design: Cross-sectional survey Aim: To describe involvement of caregivers, access to specialist palliative care, treatment goals (cure, life-prolonging, or palliation), and content of end-of-life care (physical, psychosocial, or spiritual) in a representative sample of dying persons in Belgium	Setting: General Practice Sample size: n=892 Participants: Records of deceased patients of 205 general practices	GP reports of deceased patients.	NOS Cross-sectional 7/10 (2 points not relevant)
2.3 Psychosocial care				
Survey of Italian general practitioners: knowledge, opinions, and activities of palliative care Beccaro, 2013 Italy	Design: Cross-sectional survey Aim: To conduct a national population-based study of the knowledge and activities of GPs in palliative care	Setting: General practice Sample size: n=1690 Participants: GPs	Questionnaire administered by phone	NOS Cross-sectional 6/10 (three possible points not relevant)

Physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium Meeussen, 2010[22] Belgium	Design: Mixed methods Aim: To identify GP practice in the decision to, and implement requests to hasten death.	Setting: General practice Sample size: n=13 Participants: GPs	Standardized face-to-face interviews	CASP 10/10
Case conferences between general practitioners and specialist teams to plan end of life care of people with end stage heart failure and lung disease: an exploratory pilot study Mitchell, 2014[33] Australia	Design: Pilot intervention study Aim: To evaluate a pilot of the impact of a single case conference between GP and specialist heart and lung disease services to develop a palliative care plan.	Setting: General Practice Sample size: n=21 Participants: GPs	Pilot intervention study	NOS Cohort 4/10
Brief reports General practitioners and their possible role in providing spiritual care: a qualitative study Murray, 2003[36] Scotland	Design: Qualitative study Aim: To identify their patients' holistic needs, and to discuss whether they considered that they had a role in providing 'spiritual care'.	Setting: General Practice Sample size: n=40 Participants: GPs	Qualitative interviews	CASP 7/10
General Practitioners' experiences of bereavement care and their educational support needs: a qualitative study O'Connor, 2014[34] Australia	Design: Qualitative study Aim: To explore GPs' understandings of bereavement care and their education and professional development needs in relation to bereavement care	Setting: General Practice Sample size: n=17 Participants: GPs	Qualitative	CASP 9/10

Case conferences in palliative care Shelby-James, 2012[35] Australia	Design: Qualitative study Aim: To define the content and themes of palliative care case conferences.	Setting: General Practice Sample size: n=17 Participants: Seventeen case conferences- GPs specialist palliative care GPs, specialists and nurses, patients/carers .	Content analysis of transcribed case conferences	CASP 9/10
Care for Patients in the Last Months of Life. The Belgian Sentinel Network Monitoring End-of-Life Care Study Van den Block, 2008[25] Belgium	Design: Cross-sectional survey Aim: To describe involvement of caregivers, access to specialist palliative care, treatment goals (cure, life-prolonging, or palliation), and content of end-of-life care (physical, psychosocial, or spiritual) in a representative sample of dying persons in Belgium	Setting: General Practice Sample size: n=892 Participants: Records of deceased patients of 205 general practices	GP reports of deceased patients.	NOS Cross-sectional 7/10 (2 points not relevant)
2.4 Communication and Relationship Development				
Discussing end-of-life issues in the last months of life: a nationwide study among general practitioners Abarshi, 2010[37] The Netherlands	Design: Cross-sectional survey Aim: To examine the incidence and timing of general practitioners (GPs) discussing end-of-life issues with patients whose deaths were expected	Setting: General Practice Sample size: n=252 Participants: Records of 252 Patients of GPs in a sentinel network who died non-suddenly	Chart review of identified patients.	NOS Cross-sectional 4/10 (5 possible points not relevant)

Survey of Italian general practitioners: knowledge, opinions, and activities of palliative care. Beccaro, 2013[29] Italy	Design: Cross-sectional survey Aim: To conduct a national population-based study of the knowledge and activities of GPs in palliative care	Setting: General practice Sample size: n=1690 Participants: GPs	Questionnaire administered by phone	NOS Cross-sectional 6/10 (three possible points not relevant)
Important treatment aims at the end of life: a nationwide study among GPs Claessen, 2012[38] The Netherlands	Design: Cross-sectional survey Aim: To identify treatment aims of GP and patients at time points prior to death	Setting: General Practice Sample size: n=279 Participants: Records of 279 deceased Patients	GP completed survey form	NOS Cross-sectional 7/10 (three possible points not relevant)
Reducing inequalities in care for patients with non-malignant diseases Dalkin, 2016[31] UK	Design: Mixed methods Aim: To find whether, how, and under what circumstances palliative care registrations are made for patients with non-malignant diseases in primary care.	Setting: General Practice Sample size: n=14 Participants: General Practices	Quantitative data analysis of palliative care registrations across GP practices, qualitative focus groups on effect of integrated care pathway on non-malignant palliative care registrations	NOS Cross-sectional 10/10
Participation of French general practitioners in end-of-life decisions for their hospitalized patients Ferrand, 2010[39] France	Design: Cross-sectional survey Aim: To determine the degree to which GPs participate in end of life decisions for their patients in hospital.	Setting: General Practice Sample size: n=161 Participants: GPs	Postal survey	NOS Cross-sectional 4/10 (three possible points not relevant)

General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice [26], 2005 The Netherlands	Design: Qualitative study Aim: To investigate GPs' task perception and barriers involved in palliative care.	Setting: General practice Sample size: n=22 Participants: GPs	Focus groups	CASP 9/10
General practice and specialist palliative care teams: an exploration of their working relationship from the perspective of clinical staff working in New Zealand Keane, 2017[20] New Zealand	Design: Qualitative study Aim: To explore how general practice and specialist palliative care teams (SPCTs) view their relationship in terms of partnership working	Setting: General practice and Specialist Palliative Care Teams Sample size: n=35 Participants: 6 GPs, 5 palliative care consultants, 3 allied health, 13 nurses, 8 educators and managers	Qualitative focus groups	CASP 10/10
Survey of GP medical decisions at the end of life Mitchell, 2004[21] New Zealand	Design: Cross-sectional survey Aim: To explore type and incidence of medical decisions at the end of life that hasten death made by general practitioners in New Zealand, within the context of access to palliative care.	Setting: General Practice Sample size: n=1255 Participants: GPs	National survey	NOS Cross-sectional 7/10
Family physicians and cancer care. Palliative care patients' perspective Norman, 2001[30] Canada	Design: Qualitative study Aim: 1) To explore factors that affect the integrity of palliative cancer patients' relationships with family physicians 2) To ascertain their perceptions of their family physicians roles in their care	Setting: Palliative care wards Sample size: n=25 Participants: Patients	Semi-structured interviews	CASP 8/10

Assessment of factors that influence physician decision making regarding medication use in patients with dementia at the end of life Parsons, 2014[40] Northern Ireland and Republic of Ireland	Design: Cross-sectional survey Aim: To evaluate the extent to which patient-related factors and physicians' country of practice influenced decision making regarding medication use in patients with end-stage dementia.	Setting: General Practice Sample size: n=593 Participants: GPs	Quantitative and qualitative.	NOS Cross-sectional 6/10
Healthcare professionals' perceptions toward interprofessional collaboration in palliative home care: a view from Belgium Pype, 2013[24] Belgium	Design: Qualitative study Aim: To explore the perceptions and preferences of GPs toward interprofessional collaboration.	Setting: Healthcare Professional offices Sample size: n=29 Participants: 19 GPs, 4 nurses, 1 neurologist, 1 geriatrician, 1 anesthetist, 1 palliative care specialist, 1 psychologist, 1 social worker	Focus groups	CASP 8/10
Finding common ground to achieve a "good death": family physicians working with substitute decision-makers of dying patients. Tan, 2013[41] Canada	Design: Qualitative study Aim: To describe Canadian family physicians' experiences of conflict with substitute decision-makers of dying patients to identify factors that may facilitate or hinder the end-of-life decision-making process.	Setting: General Practice Sample size: n=11 Participants: GPs	Semi-structured interviews	CASP 10/10

Care for Patients in the Last Months of Life The Belgian Sentinel Network Monitoring End-of-Life Care Study Van den Block, 2008[25] Belgium	Design: Cross-sectional survey Aim: To describe involvement of caregivers, access to specialist palliative care, treatment goals (cure, life-prolonging, or palliation), and content of end-of-life care (physical, psychosocial, or spiritual) in a representative sample of dying persons in Belgium	Setting: General Practice Sample size: n=892 Participants: Records of deceased patients of 205 general practices	GP reports of deceased patients.	NOS – cross-sectional 7/10 (2 points not relevant)
2.5 Coordination and Working in Multidisciplinary Teams				
General practitioners' use and experiences of palliative care services: South-east England Bajhwah, 2008[48] UK	Design: Cross-sectional survey Aim: To describe the satisfaction and level of coordination between GPs and palliative care services in one area.	Setting: General practice Sample size: n=180 Participants: GPs	Questionnaire	NOS Cross-sectional 6/10
General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice Groot, 2005[26] The Netherlands	Design: Qualitative study Aim: To investigate GPs' task perception and barriers involved in palliative care.	Setting: General practice Sample size: n=22 Participants: GPs	Focus groups	CASP 9/10

General practice and specialist palliative care teams: an exploration of their working relationship from the perspective of clinical staff working in New Zealand Keane, 2017[20] New Zealand	Design: Qualitative study Aim: To explore how general practice and specialist palliative care teams (SPCTs) view their relationship in terms of partnership working	Setting: General practice and Specialist Palliative Care Teams Sample size: n=35 Participants: 6 GPs, 5 palliative care consultants, 3 allied health, 13 nurses, 8 educators and managers	Qualitative focus groups	CASP 10/10
Case conferences between general practitioners and specialist teams to plan end of life care of people with end stage heart failure and lung disease: an exploratory pilot study Mitchell, 2014[33] Australia	Design: Pilot intervention study Aim: To evaluate a pilot of the impact of a single case conference between GP and specialist heart and lung disease services to develop a palliative care plan.	Setting: General Practice Sample size: n=21 Participants: GPs	Pilot intervention study	NOS Cohort 4/10
Family physicians and cancer care. Palliative care patients' perspective Norman, 2001[30] Canada	Design: Qualitative study Aim: 1) To explore factors that affect the integrity of palliative cancer patients' relationships with family physicians 2) To ascertain their perceptions of their family physicians roles in their care	Setting: Palliative care wards Sample size: n=25 Participants: Patients	Semi-structured interviews	CASP 8/10

Healthcare professionals' perceptions toward interprofessional collaboration in palliative home care: a view from Belgium Pype, 2013[24] Belgium	Design: Qualitative study Aim: To explore the perceptions and preferences of GPs toward interprofessional collaboration.	Setting: Healthcare Professional offices Sample size: n=29 Participants: 19 GPs, 4 nurses, 1 neurologist, 1 geriatrician, 1 anesthetist, 1 palliative care specialist, 1 psychologist, 1 social worker	Focus groups	CASP 8/10
Case conferences in palliative care Shelby-James, 2012[35] Australia	Design: Qualitative study Aim: To define the content and themes of palliative care case conferences.	Setting: General Practice Sample size: n=17 Participants: Seventeen case conferences- GPs specialist palliative care GPs, specialists and nurses, patients/carers.	Content analysis of transcribed case conferences	CASP 9/10

[1] NOS: Newcastle-Ottawa Scale Cross-sectional: This scale was adapted from the Newcastle-Ottawa Quality Assessment Scale for cohort studies by Herzog R et al, BMC Public Health201313:154. DOI: 10.1186/1471-2458-13-154
[2] CASP: Critical Appraisal Skills Programme qualitative checklist http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf
[3] NOS: Newcastle-Ottawa Scale Cohort: http://www.ohri.ca/programs/clinical_epidemiology/nos_manual.pdf

Appendix 3 Evidence supporting the role of general practitioners and general practice nurses in palliative care delivery

Appendix 3.1 –Perceived medical roles of GPs in providing end-of-life care

Themes	Detailed findings
Significant role in EOLC	• GPs found delivering palliative care to be satisfying, but demanding requiring a wide-range of skills[24] • High self-reported involvement in EOLC [25] • Specialist palliative care involvement influences degree of GP care. GPs more likely to be involved in people who are older, female and with non-malignant disease [25] • Specialist medical and allied health involvement more common in cancer and reduces likelihood of GP involvement. [25] • Older age, female gender, non-malignant diagnosis more likely to be have GP involvement. [25]
Practice specific medical roles (including case findings, pain management, heart failure management, breathlessness, artificial nutrition and hydration, terminal sedation)	*Case finding* • Cancer patients are significantly more likely to be identified as needing palliative care and registered that patients with non-malignant disease[31] • Reluctance to place non-malignant patients on palliative care register is to avoid uncertainty and stress given difficulties in prognostication[31] *Pain Management* • Prescribing opioids and up-titrating opioids to match pain[20] *Management of heart failure symptoms* • Wide spectrum of treatments offered, including opioids, oxygen, diuretics and haloperidol. [28] • Specialist cardiology involvement led to more anti-heart failure medicines than with GP care alone. [28] *Breathlessness* • GPs willing to follow established guidelines for dyspnoea management.[20] *Artificial nutrition and hydration (ANH)* • In advanced dementia-Response depends on definition. Dutch considered AHN as procedural interventions, where Australians considered spoon feeding as a form of ANH. [32] • All doctors were reluctant to consider tube feeding for people with advanced dementia, unless prognosis was good, as a means to clarify the patient's condition/ prognosis [32] *Initiating terminal sedation*

- Terminal sedation is offered when the patient is in distress and symptom management is ineffective 48.7 % [29], and there was persistent and unbearable suffering. [22]
- When the patient was considered incapable. [21 22] However, always with wide consultation with family, written directives, and other colleagues, including doctors and nurses[22] when determining what to do. [22 32]
- Improving the quality of life was always the guiding principle. [22 29 32]
- 63% of NZ GPs had made a prior medical decision that may have influenced time of death. These decisions included withdrawing/withholding treatment or increasing pain relief with (a) probability death would be hastened 61.8% (428), or (b) partly or explicitly to hasten death 32.6% (226). [21]
- Death was caused by a drug supplied or administered by the GP in 5.6% of cases [21]

3.2 –Psychosocial and spiritual issues

Theme	Key findings
Providing information	• Being available to deliver bad news.[29] • Understanding the patient's wishes regarding the level of knowledge about what is happening, and place of death. [29] These issues rarely discussed in Australian case conferences.[35]
Recognising and responding to suffering and psychosocial concerns	• Treatment choices are influenced by the GP perception of patient suffering [22] • GPs deliver psychosocial or spiritual care commonly and more frequently as death approaches [25] • Nature of psychosocial concerns were rarely discussed, although their management was discussed more commonly.[35] • Emotive cues were usually responded to by providing information, only occasionally with empathic responses.[35] • Case conferences dealt with emotional care, mood, and social isolation routinely [33]
Responding to Bereavement	• Visit the family during the days following the patient's death [29] *Managing uncomplicated grief* • Comfort identifying and managing uncomplicated bereavement through relying on familiarity with the carer. [34] • Lack of formal grief and bereavement education for GPs. [34] • Comfort in identifying complicated bereavement, but uncertainty what to do when identified. [34]
Addressing spiritual concerns	• Seen as a core GP responsibility [36] • Chaplains, Pastors, counsellors involved in care in about 1/4 of patients [25] • GPs made a judgement as to which patients are suitable for this sort of care. [36] • Time constraints limit the ability to follow through with spiritual issues. [36]

Appendix 3.3 – Communication between GPs, patients and carers

Theme	Key findings
Key role in communication	• GPs believe good communication between themselves, patients, carers and health professional colleagues essential to achieving good death. [24 29 37 41] • This includes building mutual trust and rapport with patients, carers and specialists[24 26 30 41] • delivering manageable amount of information[41] • understanding one another through active listening [26 41] • making informed, shared decisions[26 41]
Communicating with patients and close family/carers	*Patient experience* • Cooperation and communication between family physicians and specialists were important, but often not done well.[30] • In cancer care, family physicians provided warmth, encouragement and emotional support. [30] • Familiarity was important aspect of this, but years of previous contact not necessary.[30] *Potential causes of conflict* • Patient not disclosing all problems to the GP[26] • Existing conflicts between patient and family[26] • Unrealistic family understanding or expectations of medical ability to cure[24 26] • Family denial of terminal illness; unrealistic expectations; lack of prior relationship between physician, patient and family; lack of previous effective advance care planning. [26 41]
Initiating end-of-life discussions.	• GPs often delayed having end-of-life discussions with patients until weeks to months prior to patient death[37] • Within months to weeks of death, palliation replaced curative approaches as GP aim[25 37 38] • Patients with non-malignant disease more likely to have curative aim compared to those with malignant disease at one-month prior to death[38] • GPs are less reluctant to register patients as appropriate for palliative care if they have malignant disease due to the unpredictable trajectory of the conditions[31]
Conducting end-of-life discussions	• Discuss EoL issues with patients and substitute decision-makers[41] • Palliative home care is enhanced by stable and coherent attitudes to the care[24], but decisions can lead to conflict especially over treatment withdraw or holding, and who has the right to make key decisions[41] • GPs role in guiding patients and families, building trust, resolving conflict, is critical for achieving a good death for the patient[41] • GPs make decisions regarding the reduction of suboptimal and inappropriate medications in patients at end-of-life, including those with dementia[40] • GPs are often not contacted regarding treatment withdrawal by hospital physicians[39]

Addressing a range of topics in end-of-life discussions	• Key issues discussed in malignant and non-malignant end-of-life are primary diagnosis, incurability of illness, life expectancy or prognosis, possible medical complications, physical symptoms, psychological problems, social problems, spiritual or existential problems, palliative care options, and treatment burdens.[37] • The number of issues discussed was higher in cancer patients than any other diagnosis.[37] • Rarely were all key topics addressed [37] and GPs discussed spiritual and social issues less than physical and psychological [25 37]

Appendix 3.4 – Access to the GP, home visits, and out-of-hours services

Theme	Key findings
Being available to meet the patient and carer needs	• Patients place importance of GP availability and perceive they are more available that specialist colleagues[30] • GP contact occurred mainly when requested, not routinely[29] • Timing of GP provided care (eg visits) if ad hoc may not always be optimal for patients and carers [42] • Offering availability (eg phone contact) is very welcome. However, GPs not always available or can respond promptly when help is needed. [42] • Missed appointments are frustrating for all parties. [42] *Forms of GP availability including home care* • Clinic visits, home visits, phone support, case conferences with specialists, out-of-hours support[33 44] • GP phone support reduces anxiety and allows proactive medical care[30] • Home visits are commonly provided in terminal phase of illness[29 46] • Home visits are more common in rural regions[27];[46] , male GPs, self-employed and in a small practice[27]. • GPs viewed providing home care to be a positive experience[27]. *Out-of-hours GP services* • Common in care of palliative care patients[43 45] • Provision made difficult by vague and inadequate clinical notes and management plans[43 45] • Availability of quality clinical notes reduced hospitalization[45] • After hours doctors often lacked knowledge of local services, availability of palliative care specialist advice, or how to administer palliative care medications. [43].

Appendix 3.5 – Coordination and Working in Multidisciplinary Teams

Theme	• Key findings
Coordinating palliative care tasks.	• GPs co-ordinate tasks in EoLC, but may delegate coordination to other professionals, but some GPs dispute whether it is their role to co-ordinate[26] • For cancer patients, co-ordination can be segmented between specialist services and the GP[30] • In Belgium, GPs coordinate palliative home care teams, which reduces GP workload, useful in complex cases. But GPs lack training in co-ordination[24] • Co-ordination benefits from palliative care training of team members, GP knowledge of team member competences, agreements on care goals[24]
Liaising with patients, carers and health professionals	• GPs liaise with patients, carers and health professionals to deliver care[29 44 47] • These include family, friends, nurses (community, cancer, hospice), other GPs, hospital specialists, and pharmacists[44 47] • Collaboration is more likely with malignant patients, being younger, or those with physical, psychosocial or spiritual care needs[47] • Importance of interdisciplinary teamwork. How it manifested is related to local history. If good trust, better cooperation and willingness to cover gaps in care. [20] • GP Integration into team care important to generalists and specialists but GPs did not consider they were viewed as equal partners. [20] • Palliative care nurse co-ordinators, and case conferences promote collaboration and information sharing between primary and secondary care[20 33] • Primary care nurses report that being a member of specialist teams improved their knowledge and skills to provide palliative care[33]

Referring to and working with specialist services.

- Patients and GPs believe cooperation and communication between GPs and specialists is important.[20 24 26 29 30]
- However, some GPs felt palliative care patients can be cared for without specialist input, based on GP symptom control management and quality of local services; whereas others wanted to hand-over all care to palliative care specialists[48]
- GPs perceived referral when a problem needed more help. Specialists saw it that the problem was beyond the GP's capacity. [20] Best if specialist PC available for advice [29]
- GPs offer in-depth knowledge of patient and family, and a continuity of care[20]
- GP Integration into team care important to generalists and specialists but GPs did not consider they were viewed as equal partners. [20]
- GPs are concerned they need more palliative care-related skills education due to the low number of palliative patients[20]
- In NZ, role of GP considered to be diminished in the last few years [20 21] Main role of collaboration was considered to be the writing of a referral. [20]
- GPs perceived referral when a problem needed more help. Specialists saw it that the problem was beyond the GP's capacity. [20] Best if specialist PC available for advice [29]

Communicating with specialist teams

Facilitators of communication

- Working relationship between specialist palliative care and GPs based primarily on trust and personal liaison. [20]
- Formal case conferences facilitated interprofessional communication.[33]
- Attendance at team meetings can be difficult[24], but GPS do appreciate availability of Specialist team members for consultation.[24]

Barriers to GP-specialist communication

- Tensions between GPs and specialists over appropriate roles[20 26], particularly understanding of what integration means.[20]
- GP workload pressures[20]

Strategies to resolve communication difficulties

- Getting second opinion[41]
- Involving others to achieve common ground
- Transferring care to a colleague. [41]
- Experience also helped.[41]

Conducting multidisciplinary case conferences	• GP home based EOLC Requires a care plan. [29] • Most GPs willing to work with a specialist team to achieve a care plan. [29] • GP-specialist Case conferences are an effective means of planning and enhancing medical management [33 35] • Main topics covered in a case conference were physical symptoms, psychosocial concerns [35] • Main interactions were instructing and educating carers and patients when they were involved in the care plan [35] • Some clinicians considered the case conference as an interprofessional meeting only.[33]
Referring to and working with specialist services.	• Patients and GPs believe cooperation and communication between GPs and specialists is important.[20 24 26 29 30] • However, some GPs felt palliative care patients can be cared for without specialist input, based on GP symptom control management and quality of local services; whereas others wanted to hand-over all care to palliative care specialists[48] • GPs perceived referral when a problem needed more help. Specialists saw it that the problem was beyond the GP's capacity. [20] Best if specialist PC available for advice [29] • GPs offer in-depth knowledge of patient and family, and a continuity of care[20] • GP Integration into team care important to generalists and specialists but GPs did not consider they were viewed as equal partners. [20] • GPs are concerned they need more palliative care-related skills education due to the low number of palliative patients[20] • In NZ, role of GP considered to be diminished in the last few years [20 21] Main role of collaboration was considered to be the writing of a referral. [20] • GPs perceived referral when a problem needed more help. Specialists saw it that the problem was beyond the GP's capacity. [20] Best if specialist PC available for advice [29]

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